

Members

Rep. Vanessa Summers, Chairperson
Rep. Dennis Tyler
Rep. Cleo Duncan
Rep. Phil Hinkle
Sen. Gary Dillon
Sen. Ed Charbonneau
Sen. Connie Sipes
Sen. Sue Errington
Hugh Beebe
Dr. Gladys Beale
Michael Carmin
John E. Taylor
Dave Becker



INDIANA COMMISSION ON AUTISM

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MEETING MINUTES¹

Meeting Date: August 13, 2008
Meeting Time: 1:00 P.M.
Meeting Place: State House, 200 W. Washington St.,
Room 233
Meeting City: Indianapolis, Indiana
Meeting Number: 1

Members Present: Rep. Vanessa Summers, Chairperson; Rep. Dennis Tyler; Rep. Cleo Duncan; Rep. Phil Hinkle; Sen. Gary Dillon; Sen. Ed Charbonneau; Sen. Connie Sipes; Sen. Sue Errington; Hugh Beebe; Michael Carmin.

Members Absent: Dave Becker; John E. Taylor; Dr. Gladys Beale.

Chairwoman Summers called the meeting to order at 1:03 PM. She indicated that the Commission would hold at least four meetings this interim. Members and staff then introduced themselves.

The Chair recognized Peter Bisbecos, Director of the Division of Disability and Rehabilitative Services (DDRS) of the Family and Social Services Administration (FSSA).

Mr. Bisbecos provided a copy of his PowerPoint presentation (see Exhibit A). Mr. Bisbecos made the following main points.

On slide five, Mr. Bisbecos indicated that DDRS expended 99.4% of their state appropriation in FY 2008, or all but approximately \$5.9 M.

With slide six, he stated the slide did not tell the whole story, and actually, DDRS was serving

¹ Exhibits and other materials referenced in these minutes can be inspected and copied in the Legislative Information Center in Room 230 of the State House in Indianapolis, Indiana. Requests for copies may be mailed to the Legislative Information Center, Legislative Services Agency, 200 West Washington Street, Indianapolis, IN 46204-2789. A fee of \$0.15 per page and mailing costs will be charged for copies. These minutes are also available on the Internet at the General Assembly homepage. The URL address of the General Assembly homepage is <http://www.in.gov/legislative/>. No fee is charged for viewing, downloading, or printing minutes from the Internet.

about 20,000 persons. He stated that the Autism cost is 60% of budget.

He commented on slide 13 that it was DDRS's goal to serve 175 persons per month. He provided the following breakdown on Autism waivers- 646 on the Developmental Disabilities (DD) waiver, 663 on the Support Services waiver, and 332 in group homes, which he mentioned was a very low total compared to other persons in need of services under DDRS.

Mr. Bisbecos commented on slides 14 and 15 that there were about 2,500 individuals on the waiting list getting no services at the present time.

Representative Hinkle questioned on slide 14 if the total numbers were all autistic persons needing services. Mr. Bisbecos responded, "No", that all persons in need of services were in the totals for slide 14.

Representative Hinkle asked if slide 10 then included all persons. Mr. Bisbecos responded that it included everyone.

Representative Hinkle asked if FSSA could provide a breakdown of the data for Autism only. Mr. Bisbecos said that providing a breakdown for Autism only would be very difficult given questionable data integrity. He said the data was outdated and at least 10 years old.

Representative Hinkle replied to Mr. Bisbecos that the Commission has heard this same answer from DDRS repeatedly for at least four years. Representative Hinkle directly asked when the Commission would receive an Autism-only list for those needing services. Mr. Bisbecos responded that they could get an updated list for the next meeting.

Representative Hinkle asked would the list be a cleaned-up list. Mr. Bisbecos replied that the list would not necessarily be cleaned up, but FSSA would provide the best data available with several footnotes explaining perceived discrepancies within the data.

Representative Hinkle asked when the Commission could expect to see a clean updated list. Mr. Bisbecos stated that it could take a while to have a clean and complete update. He added that the current focus of DDRS is to get services to the people, by getting them enrolled in the program. He said the enrollment effort is taking up nearly all the DDRS resources. Mr. Bisbecos stated that he was just as frustrated with the data efforts.

Representative Hinkle asked would it be possible to see the last four years of data. Mr. Bisbecos said that would be possible, again with footnotes and caveats to explain discrepancies.

After describing slide 25, Mr. Bisbecos was informed by Representative Summers that the Commission has trouble with not receiving Autism-only data every year from DDRS. She said that she understood that DDRS is lumped in together. She said that the reports have to be more specific and show breakdowns in Autism data.

Mr. Bisbecos resumed his testimony and mentioned along with slides 32 and 33, that there was a 10% increase in successful Autism case closures, and as a result, with respect to slide 37, caseloads were going up. Mr. Bisbecos also mentioned that DDRS was approached by a Fortune 500 company to hire disabled persons. He said that adults with Autism that are high functioning are very good at repetitive work on computers and are gaining entry into career-path jobs.

Mr. Bisbecos then spoke briefly on the "Four Steps" program featuring slide 43. He said that DDRS has increasingly worked with the Department of Education to find out how many children

with Autism are attending school. He said there has been a 13% increase in the number of children with Autism that are going to be coming to DDRS. He also stated that the DD waiver renewal process is giving the DDRS an approach to look at the entire waiver system and possibly rethink the way the waiver process operates.

Representative Hinkle asked if \$6 M was the amount diverted from the DDRS budget. Mr. Bisbecos said that \$5.9 M was reverted and not used.

Representative Hinkle asked if the \$5.9 M reverted back to the state General Fund. Mr. Bisbecos replied that it did.

Following Representative Hinkle's question, a discussion between the Chair, Representative Hinkle, and Mr. Bisbecos occurred covering the data/computer system issues described above by Mr. Bisbecos.

Mr. Bisbecos described that DDRS had two computer systems: a system for entering persons in need of services and another that stores the older data. He said the storage system is garbage and that DDRS plans to replace the system. He said repeatedly that he believed the most recent three years of Autism waiver data was fairly good data.

The Chair then recognized Susan Peoples with the Autism Coalition of Indiana (Coalition) and the Autism Society of Indiana (Society) to testify.

Ms. Peoples updated the status of their ongoing contract between the Coalition and DDRS (a two-year contract). She said that the Society had held their first group meeting in April 2008. She said they began deciding their legislative agenda in June and will forward it when completed.

Chairwoman Summers encouraged Ms. Peoples to submit the legislative agenda to the Commission as soon as possible in order to produce draft legislation in time for the Commission to vote on the final report.

Ms. Peoples said that it had been decided by members of the Autism Society that the Society and the Coalition held duplicate responsibilities and roles. She said as a result, the Coalition will be rolled into the Society.

Ms. Peoples continued by stating that part of the Society's mission was to initiate encouragement towards child care entities to become involved in Autism screening. She said the Society would support the Department of Education 529 plan. She said the American Academy of Pediatrics is promoting more screening as well.

Ms. Peoples then discussed home morbid diagnoses. She said it is a huge issue that requires federal government resolution. She described the situation where Autism is diagnosed with a mental illness in a person. When this occurs, she continued, the person in need of services cannot receive federal funding for both the Autism and the mental illness. Therefore, it requires a person and their care giver to decide which condition is worse.

Ms. Peoples detailed examples where persons with two diagnoses could not receive treatment for Autism from a community health center if they went the mental illness route.

Chairwoman Summers asked if this were a state or federal issue.

Mr. Bisbecos answered on behalf of Ms. Peoples. He said that it is a federal issue and went over some differences between mentally ill and Autism funding.

Ms. Peoples continued that there is an increased need for more speech language therapists to help persons with Autism. She also mentioned the work the Society is involved with concerning the insurance mandate. She said it was important to make certain a continuity standard is put into place.

She also stated the increased need in the transfer to adult-stage services. She said adults with Autism receive less attention. Ms. Peoples said they are looking into priority waivers and are working very hard on training programs for providers. She said the insurance mandate has not altered nor taken away their recommendation of a state-level study on the cost and policies involved with care for Autism.

Ms. Peoples touched on data issues. She said incoming data was improving to better track services. She opined that providers have different computer systems and measure different things.

In closing her testimony, Ms. Peoples stated the top three considered points by the Society at the time of the meeting were to (1) expand intervention with Autism, (2) establish more treatment resource centers, and (3) encourage additional training of medical doctors to diagnose and refer Autism patients to proper care.

Representative Hinkle inquired if the three points (above) are evolving at the present time. Ms. Peoples said work to potentially revise the top three points was in progress.

Representative Duncan suggested an increase in the line item in the state budget for Autism care givers. She said it was a crime that with increasing numbers of Autism cases care givers are not given much increase in funding.

Chairwoman Summers then asked the Commission members to consider the next meeting date. After short discussion, the date was set by the Chair for Wednesday, September 10, 2008, at 1:00 PM.

Cathy Pratt with the Indiana Resource Center for Autism (Resource Center) testified following the selection of the next meeting date. Ms. Pratt passed out two items (Exhibits B and C) to help with her testimony. Exhibit B is the Easter Seals/Autism Society of America 50-state breakdown on services. Exhibit C is the Resource Center's annual report.

Ms. Pratt mentioned that Exhibit B was already outdated at the time of its release. She said it would be helpful to have model pieces of legislation regarding insurance coverage, medical waivers, and first-response training.

Ms. Pratt referred to page 27 of Exhibit C. She said that Indiana's Autism incidence rate is increasing from 1 in 128 to 1 in 113 children. In comparison, she said New Jersey has the highest incidence rate in the United States at 1 in 90 children. She said in New Jersey property taxes fund Autism detection efforts.

Senator Charbonneau asked if the incidence in New Jersey was higher than Indiana because New Jersey has more resources available to detect more children. Ms. Pratt replied that it would be difficult to determine as there is no exact count of autistic children taken in Indiana.

Ms. Pratt then discussed adult services and the creation of teams that would bring adult care agencies together. She also discussed family and first-responder training, including certified training through Indiana University.

She indicated to Chairwoman Summers that last year's Autism training bill was not wide enough

in scope as it did not include law enforcement training.

Ms. Pratt brought up a professional development Autism grant from the federal government that was awarded initially to three states: North Carolina, California, and Wisconsin. She said Indiana is the next selected state to receive a program grant at three schools.

Ms. Pratt concluded her testimony. The Chair made comment to the possibility of holding the third Commission meeting in Bloomington at the Resource Center.

Following the conclusion of announced testimony, the Chair opened the floor to others for testimony.

Kathleen Stanton-Nichols, Ph.D., Associate Professor of Adapted Physical Education with Indiana University-Purdue University Indianapolis, urged the Commission to recommend new standards for physical education for students with Autism. She stressed the importance of physical exercise, not necessarily in a gym course setting, as important to maintaining the overall health of children with Autism.

Michelle Trivetti discussed the lack of standards for behavior analyst therapists (BAT) and urged the Commission to impose tougher regulation of BATs.

With no further testimony offered, Chairwoman Summers adjourned the Commission meeting at 2:25 PM.